

Written Testimony of  
Karen Parkin-Demmons  
Parent of a child with epilepsy in the State of Connecticut

Thank You for the opportunity to submit written testimony regarding Raised HB 5303.

My name is Karen Parkin-Demmons, and I reside in Plainville, Connecticut. I am the mother of a 10-year-old boy named Jacob. I am writing in regards to Jacob and our journey with emergency medication for seizures at school. It truly has made his experience at school more complicated having rescue medication on site. Jacob has had a prescription for emergency medication (for home and school) soon after his seizures began in February 2010. He was not allowed on a regular school bus and only a school nurse was allowed to administer the medication. When field trips were organized, a nurse had to be available to go if his father, Jack, or I could not attend. At times, there was last minute notification by the nurse that there was no nurse available. Jack and I had to then re-arrange our work schedules to attend. We did not want Jacob to miss out on school sponsored events because only a nurse could administer the medication. We did what we had to do, but it was not easy. It also made Jacob feel like his parents had to always be around.

Since we never had to use the emergency medication for Jacob to date and it was a huge hassle for Jacob not to be able to ride the bus with his friends, Jack and I discussed the possibility to remove the emergency medication from school while I continue to carry it in case of an emergency. After talking with Dr. Madan Cohen (Jacob's neurologist at CCMC), his emergency medication was removed from school (and the decision for me to continue to have it on hand for emergencies made us more comfortable).

It is no longer at school so Jacob is now riding a regular school bus. It was very inconvenient to have the emergency medication at school, knowing only a nurse could administer the medication, so our decision to remove the medication made it more comfortable for Jacob to participate and feel more like a "regular" kid.